

ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LTD

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MEETING H

MINUTES OF A MEETING OF THE BOARD OF TRUSTEESheld on Saturday 3rd September 2011

PRESENT Andrew Wakelin, Chairman (AW) Sue Del Mar (SDM)	IN ATTENDANCE Allan Muir, Development Director (AM) Wendy Griffiths, Administrator (WG)	APOLOGIES Patrick Phillips
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1 Chairman's Remarks	ACTION
The Chairman welcomed people to the meeting.	

2. Minutes of previous meeting	ACTION
The minutes of the meeting that took place on Saturday 21 st May 2011 were accepted as a true record.	

3. Matters Arising	ACTION
D4 The McArdle's Disease Handbook was published on 1 st August 2011.	CLOSED
F1 The new CAF bank accounts are opened. Liaison is now taking place between the accountants, WG and SDM in order to align the bank accounts with the new Sage accounting system.	CLOSED
E2 There will be a Type Co-ordinators' meeting on the Friday evening of the Conference.	
F1 Bank accounts: New bank accounts with CAF bank are in the process of being opened.	WG
SDM mentioned that she needs details of everyone who has paid their £10, or alternatively she could pass the membership list to WG. AW stated that there should be a formal handover. AM says that one person needs to handle this, and to inform the Type Co-ordinators. Notifications of subscriptions should be handled by the office.	WG/SDM
G9 Brief to Paul Martin Design Company – to be revisited at Board meeting in new year.	AW/AM

4. Development Director's Report - attached at the end of these Minutes	
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5. Administrator's Report - attached at the end of these Minutes	
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6. Type Co-ordinators	ACTION
Christine Evans has resigned as Type IX Co-ordinator as she has too many other commitments. AW to write to thank her to ask her to remain as informal point of contact for Type IX families.	AW
A discussion was held re the recruiting of a new co-ordinator, and it was decided to look at the Type IX database to see if there is anyone suitable, and then consult the Board for their opinion, before inviting the person to the post.	AM
Agreed that the next Type Co-ordinators' meeting will be held at the Conference on the Friday evening.	CLOSED
A parent of newly diagnosed child with Type 1A may become co-ordinators. SDM to liaise.	SDM
See Type Co-ordinators' reports appended to these minutes.	

7. Finance	ACTION
Due to the accounts being transferred onto the Sage accounting system, there was no finance report.	
8. Annual Conference	ACTION
SDM says she has arranged the crèche. It will run from 1.30pm – 5pm on the Saturday and 9.30am to 1pm on the Sunday.	
There will be a Board meeting on the Sunday afternoon to reconfirm the Officer appointments. AM to book a room for one hour for a Board meeting.	AM/WG
It was suggested that rushes from the GSD film be shown at the Conference Dinner, including parts of the Bike Ride.	
Patient Experiences: SDM will ask Mary Middleton to speak. Aw to ask a Type V to speak.	SDM/AW
Larissa Lowe will be asked to speak about Disability Rights At Work.	AM
It was suggested that the Begum family in Portsmouth be asked to show their film.	AM
Workshops: i) To discuss branding ii) Disability Rights	
AW said he will check the location of the hotel as the map is wrong.	AW
9. Research	ACTION
There was a discussion as to whether or not to continue awarding grants for research. AM suggested to continue to support research, but with smaller pump-priming grants. Agreed. AW spoke about a forthcoming clinical trial of a drug in Type V. SDM said that for Type I research is lacking here, but there is a lot going on in the USA and France.	
10. Policies	ACTION
Policies: Nothing more has been done about draftg more policies at the moment.	PP/WG
Policy For Grant Applications	PP
11. Any Other Business	ACTION
It was suggested that in the newsletter a mention could be made of the memorial fund for Dr. Lee, with details of how people can contribute. Agreed that any donations to AGSD-UK in memory of Dr Lee should go into the general funds. SDM said she would write an article about this for the newsletter.	SDM

Meeting closed at 3.32 pm.

Development Director's Quarterly Report

There are a great number of activities at the moment and we are just about coping with the work load, although we have failed to produce a newsletter this quarter. Prioritising work has been a challenge but we have made a number of noteworthy achievements:

Fundraising

Steve Saunders has been assisting with the Pompey to Pompeii event but has also been submitting grant applications on our behalf. His application to the Big Lottery Fund "Awards for All" has resulted in a grant of £9500 towards the production of a short GSD Film.

Steve also has plans for a Winter Wander over the Christmas period; he'll launch his idea at the conference.

No interest in the Zip-slide, as far as I know.

We have a runner in the Brighton Marathon and have our Silver Bond next year at the London Marathon; so we'll have at least one runner.

Bike Ride

The Pompey to Pompeii event sets out in just over a week. This has been (and still is) a huge amount of work for the organisers but the participants fundraising target of £60,000 has almost been reached and corporate sponsorship is good, but not as much as had been pledged. Whilst we will net a good profit for the charity, there is a very real risk that some costs will not be met by the sponsors. Accor hotel management pledged free hotels along the route, but their franchise managers seem to have different ideas. The deal was originally worth about £20,000, although we would have chosen cheaper accommodation if paying for it ourselves. We must be prepared to lose a significant proportion of this sponsorship. Looks like an additional cost of £10,000 to the project, or £500 per cyclist.

The ride is beginning to attract media attention for a number of different reasons. A VW Camper magazine will run a 6 page spread on the journey because of our support vehicles. The Bexhill Observer will cover the event because there is local interest in many of the riders. EuroVan have given us a support vehicle and so their Publicity girl is preparing some coverage. I was interviewed by BBC Radio Solent on the Julian Clegg Show; I have been asked to be one of Julian's People and give updates throughout the event.

We have prepared a risk assessment for the ride and have Employer's and Public Liability Insurance in place for it. We have been issuing bulletins to the participants and have a dedicated website that will be updated with a blog and photos along the way.

Plan to meet Philip Maes in France (Gieres – Grenoble) and a couple in Italy have offered us tea near Turin.

GSD Film

No BBC commission but now have £13,500 for the budget. Paying Jamie Muir to film and edit. Jamie will be joining the ride for 3 weeks to capture footage along all sections of the ride and hopefully a few short interviews with riders.

We have captured a few good interviews but need to do much more after this busy period of Pompey to Pompeii and conference season.

We have purchased a new Apple MacBook and editing software for the project. We'll keep this afterwards for the charity's use.

Genzyme are commissioning a short educational film for the BMJ website. We will be referenced on the film and may also be given rights to use the physician interviews (describing the GSDs) within our film. If they are of suitable quality and content this will be a big saving in effort.

Staff

Wendy Griffiths is settling in to the role but is currently preoccupied with learning Sage and charity book-keeping,

Type IX coordinator (Christine Evans) has resigned as she finds she can't devote sufficient time to the job.

Esther James is taking her role very seriously and works closely with families, especially in Wales. She would like links for social networking sites to be added to our website.

Publications

Andrew Wakelin has published very impressive McArdle Handbook and McArdle leaflets and information cards.

Joan Fletcher has published a booklet for families and health/education professionals on Infantile Pompe disease.

We are working with Type I and III coordinators to improve website and information leaflets. We may consider booklets to add to the series. Elaine Murphy has offered additional text but we need to work with coordinators to agree content.

Conference

We seem to have chosen a bad time this year; it is schools' half term week and follows the World Muscle Society Congress in Portugal. Only one person registered to date.

There is a lot to consider but we hope to put a programme together this week and issue it and registration forms to members and supporters late next week.

Database

We have decided to abandon the on-line database, updated by members and supporters as much of the information is out of date or incorrect. We will design a bespoke database to be administered at the AGSD-UK office and will give tailored data access to Type Coordinators.

Newsletter

No newsletter was issued this quarter due to lack of submitted articles and also lack of time.

Allan Muir

Administrator's Quarterly Report

Having been with the charity for six months now (doesn't time fly?) I am gradually finding my feet. I am learning more about the charity, meeting interesting people and everyone is being very kind.

The Trustees' Information Pack is coming along nicely and is ready for a second reading of the draft.

The numbers for the Conference are very low – I hope there will be a sudden rush at the end, as I am eager to attend the Conference to meet new people and to find out more about the Association. I am slightly perturbed that with Allan being away for a large part of the next few weeks, I will be left floundering as it is my first Conference, but hopefully when he returns we will have two clear weeks to finalise the arrangements.

The biggest issue I have at the moment is the accounts. I spent a day with Bernie at the accountants in Kidderminster recently, and she was very patient and talked me through the Sage accounting system, looking over my shoulder and instructing me as I made entries. On my return to the office I thought everything she had taught me had gone in one ear and out the other, but, sitting on my own at my desk working my way through the system I am gradually finding my feet and remembering things. Allan consented to my purchasing the reference book "Sage 50 for Dummies" which explains things in a concise and easy way, but I really wish someone would write a book "Sage 50 for extra intellectually-challenged dummies" and I would probably grasp it quite easily then!! Seriously, the more I use the system and the more I read the book, the more competent I will become, and all will be well. The accountants are bringing everything up to date on the Sage accounting system for me, and then I shall hopefully be able to continue with what has been set up.

Wendy Griffiths

Type Co-ordinators' Reports

Type 1 Co-ordinator's Report – Sue Del Mar

Sue Del Mar reported Dr. Philip Lee's death and said that there will be a memorial service on October 13th. SDM will co-ordinate who will attend.

She said that next year there is a Liver Conference in Lyon, which she would like to attend.

There are no new Type 1s. SDM suggested that she and AM work on some Type 1 leaflets.

Type 2 Pompe Co-ordinator's Report - Allan Muir

Welsh patient wins access to treatment

A gentleman in Wales who had been refused Myozyme by his health board – despite WHSSC approving treatment after his appeal – has won his fight after instructing a solicitor to act on his behalf. The action was very swift and shows the benefit of this type of action over media and political campaigning. The legal action was facilitated by the AGSD-UK who put the patient in touch with the firm of solicitors who have experience of working in the field of medical rights.

Wales are currently reassessing the commissioning process for orphan therapies. I have joined other patient groups in representing the LSD community in meetings to assess and prioritise the various options for the future. The LSD groups, together with support from Genetic Alliance UK, favour the adoption of a process identical to that in England to improve access and equity within the UK. Whilst the will seems to exist, the Welsh health boards seem to favour retaining their independent processes. A decision is expected later this month (September 2011).

Infantile Pompe Disease Booklet

An information booklet is currently being printed that explains Pompe disease to families and the professionals involved with their children (healthcare, schools, social services, etc.) Part-written and edited by Joan Fletcher the booklet was designed by the Paul Martin Design Company.

Scotland

We have submitted a public petition to the committee in the Scottish Parliament regarding access to ERT for Pompe disease in Scotland. The hearing is expected to be held on October 4th or 5th. I may not be able to attend and so Joan Fletcher will represent the AGSD-UK in my place.

We have a new Pompe adult diagnosed near Aberdeen. He is eager to understand the process towards access for treatment and may well become our next test case in Scotland.

We are working closely with the MDC to examine what further political and media pressure can be applied to encourage better access to ERT in each of the devolved nations.

Untreated Diagnosed Patients

It is believed that a large number of Pompe folk were diagnosed long before ERT became available and are not aware that the treatment exists. One such lady came to light recently and we have put her in touch with the LSD expert centre in London where she hopes to receive treatment in the near future.

AMDA/IPA Pompe Conference

As chair of the IPA I will be attending the AMDA/IPA Pompe conference in San Antonio Texas on October 7/8/9/.

Genzyme Steps Forward in Pompe Disease

I have been invited to speak at Genzyme's Pompe disease symposium in Budapest in December.

Type 5 Coordinator's Report – Andrew Wakelin

McArdle Disease Handbook

The Handbook was at last published on 1 August 2011. Many thanks to Kathryn Birch (nee Wright) for her commitment to this project over 18 months. The book is a fantastic resource for people with McArdle disease and copies have already been sent out around the world – about 70 copies to date. It is priced at £7.50, plus P&P. The prices are aimed at recovering all costs, excluding the amount paid to Kathryn which was covered by a Vodafone Foundation grant of £2,400, for which we are very grateful. 100 copies were printed initially and it is intended to print a second edition with corrections (if any are reported), and an index, by 1 November.

Walking with McArdle's

The two one-week courses in Snowdonia in July and August were hugely successful despite a high cancellation rate – which we will try to reduce next year. I allowed one “bursary” due to low income. I anticipate the overall loss to be a bit over £1,000 to be borne by the Type 5 funds. Most participants had never walked with another McArdle person, all greatly valued that experience and extended their boundaries. Participants including leaders and support drivers were from: England (4), Wales (2), Scotland (1), USA (1), Ireland (1), Canada (1), Australia (1), Singapore (1). Unfortunately Steve's efforts on grant applications eventually came to nought. I did however get a supply of energy bars donated by 9-bar (enough for about 1 per day each through the two weeks).

We had some really excellent testimonials from the participants and these are on the web site to encourage others to come next year. All would like to return. The plan is to again hold two one-week courses, this time with one in Pembrokeshire (to avoid frightening people off with mountains and attract less-able people) and one again in Snowdonia. We hope to get larger groups and offer two walks each day – one easier and one harder.

McArdle Information Cards

An information card suitable to be carried in a wallet or purse has been produced. This gives summary information on the disease, outlines what assistance may be required and gives tips on recognising a severe episode and what to do. These are available for purchase via the web site.

McArdle Clinic

The London clinic is now operational, although without the full complement of staff as yet. Patients who attended Oswestry have been contacted and invited to appointments. Most are taking these up but a small number find London too daunting or difficult. The full exercise assessment cannot yet be completed as the physio has not yet been appointed. A leaflet for newly diagnosed patients has been produced and quantities are being given to the McArdle Clinic and to the two biopsy/DNA diagnostic centres in Birmingham and Sheffield. Dr Quinlivan joined the second “Walking with McArdle's” course for a day. It is a beneficial process both for her understanding of patients and for patients learning from her.

“One Step at a Time – Walking with McArdle Disease” book

I am planning another book, this one to inspire people to take exercise and to learn how to extend their boundaries safely. It is based on Stacey Reason's account of her time on the “Walk over Wales” with reflections on her coping with the disease; plus it has an information section. It will be approx 112 pages, large paperback size, have approx 200 illustrations and be printed in full colour. Sales price should be under £10. Dr Quinlivan has agreed to write a foreword. Hopefully, publication by the end of the year.